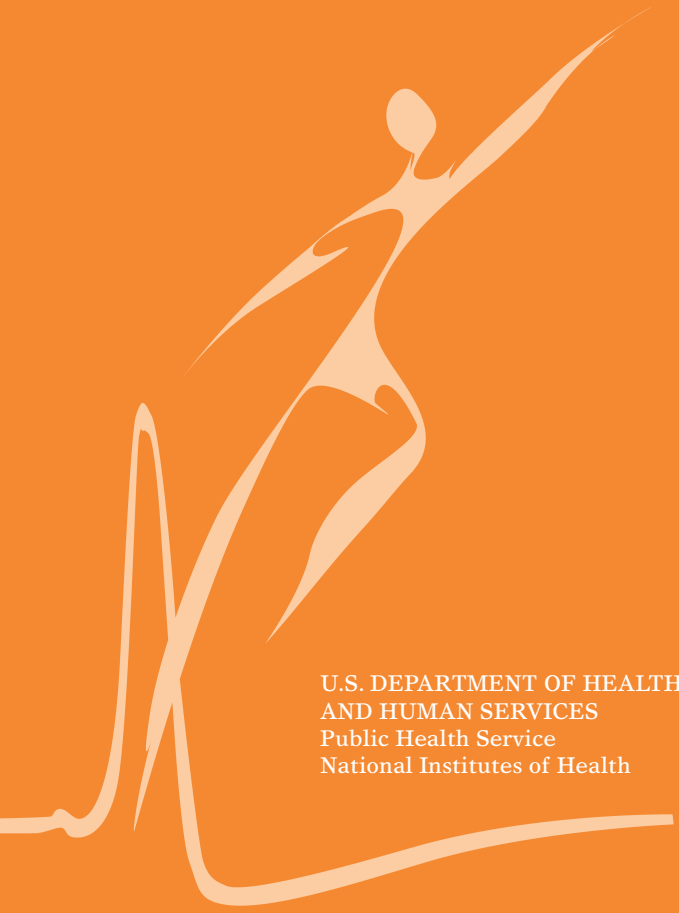
Asperger Syndrome



U.S. DEPARTMENT OF HEALTH
AND HUMAN SERVICES
Public Health Service
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Asperger Syndrome

What is Asperger syndrome?

Asperger syndrome (AS) is an autism spectrum disorder (ASD), one of a distinct group of complex neurodevelopment disorders characterized by social impairment, communication difficulties, and restrictive, repetitive, and stereotyped patterns of behavior. Other ASDs include autistic disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (usually referred to as PDD-NOS). ASDs are considered neurodevelopmental disorders and are present from infancy or early childhood. Although early diagnosis using standardized screening by age 2 is the goal, many with ASD are not detected until later because of limited social demands and support from parents and caregivers in early life.

The severity of communication and behavioral deficits, and the degree of disability, is variable in those affected by ASD. Some individuals with ASD are severely disabled and require very substantial support for basic activities of daily living. Asperger syndrome is considered by many to be the mildest form of ASD and is synonymous with the most highly functioning individuals with ASD.

Two core features of autism are: a) social and communication deficits and b) fixated interests and repetitive behaviors. The social communication deficits in highly functioning persons with Asperger syndrome include lack of the normal back and forth conversation; lack of typical eye contact, body language, and facial expression; and trouble maintaining relationships. Fixated interests and repetitive behaviors include repetitive use of objects or phrases, stereotyped movements, and excessive attachment to routines, objects, or interests. Persons with ASD may also respond to sensory aspects of their environment with unusual indifference or excessive interest.

The prevalence of AS is not well established. It is often not recognized before age 5 or 6 because language development is normal. Although ASD varies significantly in character and severity, it occurs in all ethnic and socioeconomic groups and affects every age group. Experts estimate that as many as 1 in 88 children age 8 will have an autism spectrum disorder.[1] No studies have yet been conducted to determine the incidence of Asperger syndrome in adult populations, but studies of children with the disorder suggest that their problems with socialization and communication continue into adulthood. Some of these children develop additional psychiatric symptoms and disorders in adolescence and adulthood. Males are four times more likely than girls to have ASD.

1 Centers for Disease Control and Prevention. Morbidity and Mortality Weekly Report, March 30, 2012.

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Why is it called Asperger syndrome?

In 1944, an Austrian pediatrician named Hans Asperger observed four children in his practice who had difficulty integrating socially. Although their intelligence appeared normal, the children lacked nonverbal communication skills, failed to demonstrate empathy with their peers, and were physically awkward. Their speech was either disjointed or overly formal, and their all-absorbing interest in a single topic dominated their conversations. Dr. Asperger called the condition "autistic psychopathy" and described it as a personality disorder primarily marked by social isolation.

Asperger's observations, published in German, were not widely known until 1981, when an English doctor named Lorna Wing published a series of case studies of children showing similar symptoms, which she called "Asperger's" syndrome. Wing's writings were widely published and popularized. AS became a distinct disease and diagnosis in 1992, when it was included in the tenth published edition of the World Health Organization's diagnostic manual, International Classification of Diseases (ICD-10). In 1994 it was added to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), the American Psychiatric Association's diagnostic reference

book. However, scientific studies have not been able to definitively differentiate Asperger syndrome from highly functioning autism. Because autism is defined by a common set of behaviors, proposed changes to be announced in DSM-V, which are expected to take effect in mid-2013, will represent the various forms under a single diagnostic category, ASD.

What are some common signs or symptoms?

Children with Asperger syndrome may have speech marked by a lack of rhythm, an odd inflection, or a monotone pitch. They often lack the ability to modulate the volume of their voice to match their surroundings. For example, they may have to be reminded to talk softly every time they enter a library or a movie theatre.

Unlike the severe withdrawal from the rest of the world that is characteristic of autism, children with Asperger syndrome are isolated because of their poor social skills and narrow interests. Children with the disorder will gather enormous amounts of factual information about their favorite subject and will talk incessantly about it, but the conversation may seem like a random collection of facts or statistics, with no point or conclusion. They may approach other people, but make normal conversation difficult by eccentric behaviors or by wanting only to talk about their singular interest.

Many children with AS are highly active in early childhood, but some may not

reach milestones as early as other children regarding motor skills such as pedaling a bike, catching a ball, or climbing outdoor play equipment. They are often awkward and poorly coordinated with a walk that can appear either stilted or bouncy.

Some children with AS may develop anxiety or depression in young adulthood. Other conditions that often co-exist with Asperger syndrome are Attention Deficit Hyperactivity Disorder (ADHD), tic disorders (such as Tourette syndrome), depression, anxiety disorders, and Obsessive Compulsive Disorder (OCD).

What causes Asperger syndrome?

The cause of ASD, including Asperger syndrome, is not known. Current research points to brain abnormalities in Asperger syndrome. Using advanced brain imaging techniques, scientists have revealed structural and functional differences in specific regions of the brains of children who have Asperger syndrome versus those who do not have the disorder. These differences may be caused by the abnormal migration of embryonic cells during fetal development that affects brain structure and "wiring" in early childhood and then goes on to affect the neural circuits that control thought and behavior.

For example, one study found a reduction of brain activity in the frontal lobe of children with Asperger syndrome when they were asked to respond to tasks that required them to use their judgment. Another study found differences in activity when children were asked to respond to facial expressions. A

different study investigating brain function in adults with AS revealed abnormal levels of specific proteins that correlate with obsessive and repetitive behaviors.

Scientists have long suspected that there are genetic and environmental components to Asperger syndrome and the other ASDs because of their tendency to run in families and their high concordance in twins. Additional evidence for the link between inherited genetic mutations and AS was observed in the higher incidence of family members who have behavioral symptoms similar to AS but in a more limited form, including slight difficulties with social interaction, language, or reading.

A specific gene for Asperger syndrome, however, has never been identified. Instead, the most recent research indicates that there are most likely a common group of genes whose variations or deletions make an individual vulnerable to developing ASD. This combination of genetic variations or deletions, in combination with yet unidentified environmental insults, probably determines the severity and symptoms for each individual with Asperger syndrome.

How is it diagnosed?

The diagnosis of Asperger syndrome is complicated by the lack of a standardized diagnostic test. In fact, because there are several screening instruments in current use, each with different criteria, the same child could receive different diagnoses, depending on the screening tool the doctor uses.

Asperger syndrome, also sometimes called high-functioning autism (HFA), is viewed as being on the mild end of the ASD spectrum with symptoms that differ in degree from autistic disorder.

Some of the autistic behaviors may be apparent in the first few months of a child's life, or they may not become evident until later.

The diagnosis of Asperger syndrome and all other autism spectrum disorders is done as part of a two-stage process. The first stage begins with developmental screening during a "well-child" check-up with a family doctor or pediatrician. The second stage is a comprehensive team evaluation to either rule in or rule out AS. This team generally includes a psychologist, neurologist, psychiatrist, speech therapist, and additional professionals who have expertise in diagnosing children with AS.

The comprehensive evaluation includes neurologic and genetic assessment, with in-depth cognitive and language testing to establish IQ and evaluate psychomotor function, verbal and non-verbal strengths and weaknesses, style of learning, and independent living skills. An assessment of communication strengths and weaknesses includes evaluating non-verbal forms of communication (gaze and gestures); the use of non-literal language (metaphor, irony, absurdities, and humor); patterns of inflection, stress and volume modulation; pragmatics (turn-taking and sensitivity to verbal cues); and the content, clarity, and coherence of conversation. The physician will look at the testing results and combine them with the child's developmental history and current symptoms to make a diagnosis.

Are there treatments available?

There is no cure for Asperger syndrome and the autism spectrum disorders. The ideal treatment plan coordinates therapies and interventions that meet the specific needs of individual children. There is no single best treatment package for all children with AS, but most health care professionals agree that early intervention is best.

An effective treatment program builds on the child's interests, offers a predictable schedule, teaches tasks as a series of simple steps, actively engages the child's attention in highly structured activities, and provides regular reinforcement of behavior. This kind of program generally includes:

- social skills training, a form of group therapy that teaches children with AS the skills they need to interact more successfully with other children
- cognitive behavioral therapy, a type of "talk" therapy that can help the more explosive or anxious children to manage their emotions better and cut back on obsessive interests and repetitive routines
- medication, if necessary, for co-existing conditions such as depression and anxiety
- occupational or physical therapy, for children with sensory integration problems or poor motor coordination
- specialized speech/language therapy, to help children who have trouble with the pragmatics of speech—the give and take of normal conversation, and

- parent training and support, to teach parents behavioral techniques to use at home.

Do children with AS get better?

With effective treatment, children with AS can learn to overcome their disabilities, but they may still find social situations and personal relationships challenging. Many adults with Asperger syndrome work successfully in mainstream jobs, although they may continue to need encouragement and moral support to maintain an independent life.

What research is being done?

Within the Federal government, the National Institute of Neurological Disorders and Stroke (NINDS), a part of the National Institutes of Health (NIH), supports and conducts research on the brain and nervous system. The NINDS and other NIH components support research on autism spectrum disorders, either at NIH laboratories or through grants to major research institutions across the country.

In 1997, at the request of Congress, the NIH formed its Autism Coordinating Committee (NIH/ACC) to enhance the quality, pace, and coordination of efforts at the NIH to find a cure for autism (*http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders/nih-initiatives/nih-autism-coordinating-committee.shtml*). The NIH/ACC involves the participation of seven NIH Institutes and Centers: the National Institute of Neurological Disorders and Stroke, the *Eunice Kennedy Shriver* National Institute

of Child Health and Human Development, the National Institute of Mental Health, the National Institute on Deafness and Other Communication Disorders, the National Institute of Environmental Health Sciences, the National Institute of Nursing Research, and the National Center on Complementary and Alternative Medicine. The NIH/ACC has been instrumental in the understanding of and advances in ASD research (*http://iacc.hhs.gov/strategic-plan/2011/index.shtml*). The NIH/ACC also participates in the broader Federal Interagency Autism Coordinating Committee (IACC) that is composed of representatives from various component agencies of the U.S. Department of Health and Human Services, as well as the U.S. Department of Education and other government organizations.

In fiscal years 2007 and 2008, NIH began funding the 11 Autism Centers of Excellence (ACE), coordinated by the NIH/ACC. The ACEs are investigating early brain development and functioning, social interactions in infants, rare genetic variants and mutations, associations between autism-related genes and physical traits, possible environmental risk factors and biomarkers, and a potential new medication treatment.

Where can I get more information?

For more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's Brain Resources and Information Network (BRAIN) at:

BRAIN
P.O. Box 5801
Bethesda, MD 20824
800- 352-9424
www.ninds.nih.gov

Information also is available from the following organizations:

MAAP Services for Autism and Asperger Syndrome
P.O. Box 524
Crown Point, IN 4630
219-662-1311
www.aspergersyndrome.org

Autism Science Foundation
419 Lafayette Street, 2nd Floor
New York, NY 10003
646 -723-3978
www.autismsciencefoundation.org

Autism Society of America
4340 East-West Highway, Suite 350
Bethesda, MD 20814
301-657-0881
800-328-8476
www.autism-society.org

Autism Speaks, Inc.
1 East 33rd Street, 4th Floor
New York, NY 10016
212-252-8584
www.autismspeaks.org

Organization for Autism Research
2000 North 14th Street, Suite 710
Arlington, VA 22201
703-243-9710
www.researchautism.org

Centers for Disease Control and Prevention
Department of Health and Human Services
Office of Public Inquiries
1600 Clifton Road
Atlanta, GA 30333
404-639-3311 or 404-639-3543
800-232-4636
www.cdc.gov

National Dissemination Center for Children with Disabilities
1825 Connecticut Avenue, NW, Suite 700
Washington, DC 20009
202-844-8200
800-695-0285
www.nichcy.org

***Eunice Kennedy Shriver* National Institute of Child Health and Human Development Information Resource Center**
P.O. Box 3006
Rockville, MD 20847
800-370-2943
888-320-6942 (TTY)
www.nichd.nih.gov

National Institute of Environmental Health Sciences
National Institutes of Health, DHHS
111 T.W. Alexander Drive
Research Triangle Park, NC 27709
919-541-3345
www.niehs.nih.gov

National Institute of Mental Health
National Institutes of Health, DHHS
6001 Executive Boulevard
Room 8184, MSC 9663
Bethesda, MD 20892-9663
301-443-4513
866-615-6464
301-443-8431 (TTY)
www.nimh.nih.gov

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